



The following questions and comments received during and after the November 20th, 2018 presentation designed to introduce the Supports Intensity Scale-Adult VersionTM (SIS-A)TM assessment in Vermont, have been edited for clarity.

1. The SIS-A is normed on ages 16-64...Is there a tool for older adults?

Response: In the SIS standardization sample, 11% was 60 years and older. Although the norms go from 16 to 64, there is no reason to think the norms would not be similar if the scale were to go up to 65 or 66. For planning purposes, there are items and subscales on the SIS-A which are not fully applicable to people over 64. For instance, the "employment subscale" is not particularly useful for older adults who choose not to work because they are retired. If there is a need for an assessment that can be used with everyone served by the State, the SIS is just as appropriate as anything else that might be used.

AAIDD is in the early phase of exploring a separate extension of the SIS-A specifically aimed at the aging population, and which can be integrated with SIS results from other populations.

2. How often would the SIS-A be administered?

Response: AAIDD recently investigated the stability of SIS-A scores (Shogren et al., in press) by examining longitudinal data from adults with intellectual disability who were reassessed one to three years following their initial SIS-A assessment. Findings support the stability of SIS-A scores over a one to three-year period. We could not examine the stability of SIS-A scores over a period longer than 3 years because AAIDD does not have data to examine changes beyond the 3-year cycle. Findings support the 3-year time frame between reassessments that has been adopted by many jurisdictions. AAIDD has no basis to recommend that a longer time frame would or would not yield different results and is in the process of doing further research regarding the stability of SIS-A scores over longer periods of time. Jurisdictions choosing a longer time frame should have data to justify their decision.

3. What section covers sexuality needs as well as criminal behavior?

Response: While there is no specific section of SIS-A that covers only sexuality and/or criminal behavior, these two concerns are captured—through several items in the assessment. Specifically, in Section 1B (Exceptional Behavioral Support Needs), two items address support needs for sexual behavior concerns (*Prevention of nonaggressive but inappropriate sexual behavior*; *Prevention of sexual aggression*), both of which could be perceived as “criminal” behavior. These support needs also may influence support that is needed on a day-to-day basis,

and therefore is captured throughout the assessment in the activities listed in Section 2 and Section 3.

Because each person's support needs are unique, the impact of these behavioral concerns should be discussed with the respondent group to identify the appropriate ratings that describe the individual's unique support needs.

In addition to the behavioral support needs in Section 1B, support for safe sex (Health and Safety Activities) as well as support for intimate relationships (Social Activities) are captured in Section 2. During the assessment process, it is important that all information impacting support needs, including sexuality and/or criminal behavior, is discussed with the interviewer to ensure that the ratings reflect the impact of these or other influences on support needs.

4. What is the process if the respondents don't agree?

Response: While it is more common that during the assessment process and discussion, respondents will agree on the rating that most accurately reflect an individual's support needs, there are times when not all present will agree with a specific rating. Interviewers are trained to identify this issue, work with respondents, and identify the ratings that most accurately reflect a person's support needs. The interviewer's role is to listen very closely to respondents, probe for additional information when needed, and ultimately to make the final decision on the best rating for each item. On the assessment, documentation can be made regarding the nature of disagreements.

5. Is this webinar outline going to be disseminated to participants?

Response: The webinar will be available for viewing as set by AAIDD and DAIL-DDSD for a limited time.

6. Will the slide deck used today be available as a PDF?

Response: While the webinar will be available for viewing, the slide deck will not be disseminated to individuals.

7. Can you show us the results of a scored assessment?

Response: AAIDD is working with DAIL-DDSD to identify the most appropriate ways to assist stakeholders in Vermont with learning more about the information that is created by SIS-A assessments.

8. Is there any room in the definition of "successful" for the individual to indicate when they would feel successful rather than having an interview/respondent define standard community success?

Response: The definition of "success" as used during a SIS-A assessment, is defined as "fully participating in community life". This definition must remain consistent across all SIS-A assessments so that the tool can measure the relative intensity of supports needed for this level of success.

9. Is the SIS-A correlated with the WAIS-IV, Vineland or ABAS-3?

Response: The SIS-A measures the pattern and intensity of support needs individuals with intellectual and other developmental disabilities need to participate in community life compared with people in the general population. This assessment is different from the WAIS-IV which measures adult intelligence and cognitive ability, and the Vineland and ABAS-3 which are adaptive behavior scales. A key distinction between the SIS and adaptive behavior scales is that the adaptive behavior stems are “skills” needed to successfully function in society, while SIS items are activities that a person does during participation in everyday life. Adaptive behavior responses address level of mastery or performance. Responses on a support needs scale reflect intensity of supports needed to accomplish the task (Supports Intensity Scale User’s Manual, 2004).

10. Who chooses the “respondents”? What assurance is there that “respondents” are representing the goals/interests of the individual?

Response: Respondents who accurately describe the individual’s support needs is the key to a successful SIS-A assessment. Respondents must have known the individual for at least 3 months and must have had recent opportunities to observe the individual participate in one or more environments for long periods of time (at least several hours per setting). Respondents each bring a unique perspective of support needs to the assessment process. AAIDD does not dictate the specific people who make up each respondent group, but generally respondents include people such as the individual receiving services, family member, provider personnel, service coordinators, friends, etc. Jurisdictions who use the SIS-A assessment are encouraged to develop a process to ensure that all necessary respondents are invited to attend the SIS-A assessment meeting.

11. Will Vermont use the SIS-C for children with DD if it adopts the SIS-A?

Response: Vermont has not discussed with AAIDD use of the Supports Intensity Scale-Children’s Version™.

12. How does SIS bring up sleep disturbances and measure cases where people are up all night?

Response: SIS-A identifies the pattern and intensity of support needs for success---full participation in community life. Every individual has unique influences which impact support needs. For some, sleep disturbances are one of these influences. Influences on support needs should be discussed and identified so that the influences are captured within the ratings to show the specific story of each person’s support needs. As an example, the frequency of support rating can capture the support that is needed for specific activities -whether it is needed less than monthly; at least once a month, but not every week; at least once a week, but not every day; at least every day; or 24 hours per day.

13. Is it possible to do one section as support needs change or does the whole assessment need to be completed [each interval]?

Response: If there is a significant change in an individual’s support needs and a new assessment is required, the SIS-A assessment should be completed in its entirety.

14. What is training for SIS-A like? How often is it offered, where, etc.?

Response: Training for interviewers is customized to fit the needs of the jurisdiction. In general, training consists of an orientation (to help new interviewers understand all aspects of the assessment), guided practice assessments, as well as Interviewer Qualification and Reliability Reviews (which are required on an annual basis) to ensure interviewers are facilitating SIS-A assessment with fidelity, and in accordance with AAIDD guidelines.

15. Did the 2015 update include any consideration to “trauma-informed” services and supports when identifying support needs?

Response: SIS-A identifies the pattern and intensity of support needs-regardless of current services. Each person has unique support needs and trauma may influence a person’s support needs. SIS-A capture support needs and therefore, would capture trauma’s effects on these support needs. It is important that respondents identify and discuss the individual’s support needs and explain to the interviewer the influences that impact the person’s support.

16. In other states that have implemented use of SIS, who are typically the interviewers? Program staff? State employees?

Response: Each jurisdiction determines the system that works best for the implementation of its assessment to include who administers the assessment. This may include state employees, case managers, independent 3rd party interviewers, etc.

17. What section covers parenting?

Response: SIS-A does not capture support needs typically associated with parenting. Support to assist with parenting can be captured through other means as determined by the jurisdiction.

18. How are changing needs in specific areas assessed after the original assessment is completed?

Response: While support needs do not typically significantly change within a short period of time, situations do occur in which a person’s support needs may change (i.e. significant change in medical concerns, behavioral concerns, living arrangements, etc.). Each jurisdiction determines how changing support needs will be considered and may involve the need to complete a new SIS-A assessment.

19. Are we able to build the SIS-A within our Electronic Health Records? Proprietary?

Response: Should Vermont decide to use the SIS-A assessment, discussions will occur regarding the use of the AAIDD SIS-A online database or other methods of storing the information from each assessment.

The following responses address several concerns raised about the SIS assessment, and are summarized below:

Concern 1: Medical and behavioral content items on the SIS are limited.

Response: The items listed on SIS-A (Section 1A) identify current exceptional medical support needs and includes support for ostomy care (including tracheostomy and other stomas),

respiratory care (including inhalation/oxygen therapy, postural drainage, chest physical therapy, and suctioning), allergies (including the support to avoid triggers for allergic reactions and managing allergic reactions such as the use of an epi-pen) as well as 12 other current exceptional medical support needs. In the situation where the 18 items specifically listed on the SIS-A assessment do not cover a person's current exceptional medical support needs, there is the opportunity to add to this by documenting any other current exceptional medical support needs.

In addition to medical support needs, the SIS-A assessment also shows (throughout section 2 & 3) the impact of the items listed above or other medical support needs in day-to-day life activities. For instance, the significant support needed day-to-day for life activities for someone with dementia, will be shown throughout the ratings in Section 2 & 3, to give a full and complete picture of the person's support needs.

Concern 2: The three scoring choices encompass a broad range of needs.

Response: The rating options in Section 1 will show the support currently needed. For instance, when discussing the support needed for lifting and transferring, it is important to discuss the intensity of support that is currently needed. This discussion can include if the person currently needs support from 1 person or more than 1 person, use of mechanical lifts, etc. Additional documentation can be added to the assessment as needed (documentation can be added to any items) to show and to document the exact nature of the support needs. A critical assumption underlying Section 1 of SIS-A is that certain medical conditions and challenging behaviors can determine that a person needs substantial support, regardless of his or her relative intensity of support needs in other life areas assessed in that standardized portion of the Scale (Section 2). Information and discussion from Section 1 will identify and capture the individual's support needs for current exceptional medical/behavioral concerns and can provide "checks and balances" against the standard scores that are generated from the responses in Section 2.

Concern 3: The absence of a Therapy Services section in the behavioral section and no recognition of Trauma, Borderline Personality Disorder, etc.

Response: The SIS-A assessment identifies support needs and does not rate a diagnosis. Individuals with a diagnosis (such as Borderline Personality Disorder, PTSD) may have differing support needs, and therefore it is important that the ratings reflect current support needs rather than only the diagnosis Therapy services support (Section 1 #15) includes support in implementing recommendations from a variety of therapy to include physical therapy, occupational therapy, speech-language therapy and individual or group psychological therapy. In addition, any support needed for individual behavioral concerns that might be captured with other therapies (e.g. DBT, etc.) is captured with the current support for prevention of the behavioral concern (e.g. prevention of emotional outbursts, prevention of assaults or injuries to others, etc.). As with the current exceptional medical support needs, any current exceptional behavioral support needs that are not captured in 12 listed items can be captured with the item – Prevention of other serious behavior problem.

Concern 4: There is no specific section on communication.

Response: While 2F #7 (**Communicating** with others about personal needs) is one example of communicating, there are many other life activities associated with communication throughout the SIS-A assessment--- these are often identified by the verbs-interacting or socializing. Section 2B #7 – **Interacting** with Community Members – is an item that focuses on supports to promote positive and effective interactions with the public in whatever context they occur. Section 2F #6, - **Socializing** Within the Household – focuses on supports to promote the use of positive interactions and communication in the household as well as learning to respect the privacy of others with whom the person lives. These are but 2 examples of how the SIS-A identifies supports related to communication.

The support needed to communicate/interact/socialize in a variety of settings, situations, activities and with familiar or unfamiliar people is captured in many questions within SIS-A. Each of these items focus on communication/interaction/socialization and is specific to the activity. However, once the assessment is completed, the data will show the supports the individual needs to successfully communicate/interact/socialize throughout the same activities, environments and with the same people as other adults within the community.

Concern 5: Using the SIS as a tool for funding and moving our current funding process further away from being person centered.

Response: Information on how the SIS is used in the funding process can be found at: http://aaidd.org/docs/default-source/sis-docs/supportneeds.pdf?sfvrsn=a88b3021_0

Concern 6: The SIS specifically excludes context in the assessment process, which is a major component of a person-centered planning plan.

Response: Support needs are captured in the variety of life activities throughout the SIS-A. Context is central to all items of the SIS-A due to how they influence the support the individual needs for successful and participation in community life.

Concern 7: The low reliability scores reported.

Response: Additional information and current research on the psychometric properties of the SIS-A can be found here: http://aaidd.org/docs/default-source/sis-docs/evidence-for-the-reliabilityandvalidity-of-the-sis.pdf?sfvrsn=7ed3021_0

Concern 8: How the needs listed on the front page of the tool would be used *in conjunction with* the results of the formal assessment to determine need.

Response: The SIS-A measure the pattern and intensity of supports an individual with an intellectual and other developmental disabilities need to be successful in the community. Listed

in the Demographics first page under the heading “Presence of Disabilities” are examples of diagnoses that are part of the conversation around influences on support needs.

All items on the front page of the assessment are used for data analysis, and do not equate to a specific rating within the assessment.

All items listed in this question influence the support that an individual need for success and the support needed is captured in the variety of life activities of the SIS-A. It is important to note, that while people may have the same diagnosis, the support that is needed can vary significantly from person to person, and therefore, each question within the SIS-A must be asked so that these challenges and the influence they have on a person’s support needs can be accurately reflected within the assessment.